

Developmentally appropriate healthcare for young people

Farre, Albert; Wood, Victoria; Rapley, Tim; Parr, Jeremy R.; Reape, Debbie; McDonagh, Janet E.

DOI:

[10.1136/archdischild-2014-306749](https://doi.org/10.1136/archdischild-2014-306749)

License:

Other (please specify with Rights Statement)

Document Version

Peer reviewed version

Citation for published version (Harvard):

Farre, A, Wood, V, Rapley, T, Parr, JR, Reape, D & McDonagh, JE 2015, 'Developmentally appropriate healthcare for young people: A scoping study', *Archives of Disease in Childhood*, vol. 100, no. 2, pp. 144-151. <https://doi.org/10.1136/archdischild-2014-306749>

[Link to publication on Research at Birmingham portal](#)

Publisher Rights Statement:

Checked for eligibility: 17/01/2017.

Copyright © 2017 BMJ Publishing Group Ltd & Royal College of Paediatrics and Child Health. All rights reserved. Farre A, Wood V, Rapley T, et al. Arch Dis Child 2015;100:144–151. doi: 10.1136/archdischild-2014-306749

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Developmentally appropriate healthcare for young people: a scoping study

Albert Farre^{1*}, Victoria Wood², Tim Rapley², Jeremy R Parr³, Debbie Reape⁴, Janet E McDonagh¹

¹School of Immunity and Infection, University of Birmingham, Birmingham, UK

²Institute of Health and Society, Newcastle University, Newcastle upon Tyne, UK

³Institute of Neuroscience, Newcastle University, Newcastle upon Tyne, UK

⁴Northumbria Healthcare NHS Foundation Trust, Tyne and Wear, UK

*Corresponding author: a.farre@bham.ac.uk

ABSTRACT

Background: There is increasing recognition of the importance of providing quality healthcare to meet the biopsychosocial needs of young people. “Developmentally Appropriate Healthcare” (DAH) for young people is one term used to explain what these services consist of. However, this term remains ill defined.

Aims: (i) To analyse the use of the term DAH in the scientific literature and (ii) to identify and explore the range of meanings attributed to the term in relation to young people.

Methods: A scoping review was conducted to map the presence of the term DAH in the literature. To analyse the use and meanings attributed to the DAH terminology, data underwent qualitative content analysis using a summative approach.

Results: 62 papers were selected and subjected to content analysis. An explicit definition of DAH was provided in only 1 of the 85 uses of the term DAH within the data set and in none of the 58 uses of the prefix ‘developmentally appropriate’. A link between the use of the term DAH and the domains of adolescent medicine, young people, chronic conditions and transitional care was identified; as were the core ideas underpinning the use of DAH.

Conclusions: There is a need for consistency in the use of the term DAH for young people, the related stage-of-life terminology and age range criteria. Consensus is now needed as to the content and range of a formal conceptual and operational definition.

KEYWORDS

Developmentally Appropriate Healthcare; Adolescent Development; Adolescent Health Services; Adolescents; Young Adults

What is already known on this topic

- In recent years, research has increasingly highlighted the need for healthcare for young people aged 10-24 years to be different from that received by children and adults.
- Developmentally Appropriate Healthcare is considered a key principle underpinning the practice of young-person-centred healthcare, i.e. responsive to the evolving developmental needs of young people aged 10-24 years.
- The provision of consistent, co-ordinated healthcare over adolescence and young adulthood has been reported as a key issue impacting upon young people’s biomedical outcomes as well as upon their engagement with healthcare services.

What this study adds

- Despite its increasing relevance, the term Developmentally Appropriate Healthcare remains ill defined.
- Consensus about critical aspects of DAH is required (such as the related stage-of-life terminology and age range cut-off points); a definition of DAH is needed.
- This consensus would lead to the production of a stronger body of evidence about DAH services, the development of quality criteria, and allow future evaluation.

INTRODUCTION

Provision of effective healthcare services during adolescence and young adulthood requires acknowledgement of the breadth and intensity of biopsychosocial development during this period, and identification of the needs that set this population apart from children and adults [1].

The need for healthcare for young people (defined by the WHO as age 10 - 24 years) [2] to be different from that received by children and adults has received much attention in recent years [1,3–5]. The provision of consistent, co-ordinated healthcare over this important period of development is a key issue impacting upon young people’s biomedical outcomes [6,7]; their adherence to therapy [8]; satisfaction with healthcare provision [9]; engagement with healthcare services [10]; self-care practices [11]; and their achievement as self-reliant, independent and productive members of society [12].

However, at present health care services that specifically address the needs of young people are not universally available even in countries with well developed, funded healthcare provision [4].

“Developmentally Appropriate Healthcare” (DAH) for young people is one term used to explain what these specific services consist of. Whilst acknowledging the importance and growing awareness of youth-friendly health services in both primary and specialist care [5], the term DAH is of particular interest as it focuses on development (rather than chronological age) and has the potential to convey the dynamic nature of adolescent and young adult development as a defining characteristic of health services. However, the term DAH remains ill defined and, as such, its conceptual meaning and operational formulation are currently too vague to enable the production of a well-defined recognisable body of evidence.

This study was conceived as a first step towards a formal accepted definition of DAH, in addition to being an enabler for further research with the potential to explore how the term DAH overlaps and differs from other terms currently in use to refer to the provision of healthcare for young people (such as “age-appropriate”, “adolescent-friendly” or “youth-friendly”). In so doing, the study will inform the design, implementation and evaluation of consistent and comparable DAH services for young people.

The aims of this study are therefore to (i) analyse the use of the term DAH in the scientific literature and (ii) identify and explore the range of meanings attributed to the term in relation to young people.

DATA AND METHODS

A scoping review [13,14] was conducted to map the presence of the term DAH in the literature. The relevance of this method to this particular study lies in the lack of an explicit conceptual definition of DAH in the literature, which in turn made other forms of literature review or research synthesis problematic.

Since we intended to map a multi-word concept that is not determined a priori by age group and that focuses on the term ‘development’ rather than age related terms, our search strategy combined the following 8 phrase searching elements in 4 Boolean queries: "developmentally appropriate healthcare", "healthcare developmentally appropriate", "developmentally appropriate health care", "health care developmentally appropriate", "developmentally appropriate health", "health developmentally appropriate", "developmentally appropriate care" and "care developmentally appropriate". The search

queries covered title, abstract, keywords and full-text search where available and were conducted across 7 bibliographic databases (PubMed, PsycARTICLES, Social Policy and Practice, HMIC Health Management Information Consortium, Journals@Ovid, PsycINFO, Scopus) and Google Scholar. The searches were conducted in February 2013 and not restricted by publication date. The search terms were applied in English only; beyond that, language did not constitute an exclusion criterion. We hand-searched the literature and consulted domain experts to identify additional publications.

The results of the searches were assessed for the presence of the term DAH. Conference abstracts and book chapters were not included. Studies were included if they used the term DAH in the articles (n=122), or used closely related variations of the term, such as 'developmentally appropriate care' and 'developmentally appropriate transitional care' (n=17). The articles (n=141) were refined by excluding duplicate entries (n=57) and excluding articles that focused on other areas, such as education or developmental psychology, and did not pertain to health or health services research (n=22). A total of 62 papers (Table 1) were then subjected to analysis.

To explore the use and meanings attributed to the term DAH, the search results then underwent qualitative content analysis [15] in two stages:

First, articles were subjected to manifest content analysis [16–18] to identify preliminary patterns in the data and contextualise the use of the term DAH. Articles were categorised by: authors' country of institutional affiliation; topic/area of research; health condition; age group and/or developmental stage; and year of publication.

Second, articles were subjected to latent content analysis [16–18] to identify the core ideas attached to the term DAH in relation to young people, as well as the supporting empirical evidence when provided.

The coding and analysis process employed NVivo 10 software and followed the principles of a summative approach to qualitative content analysis [15].

RESULTS

The context of use of the term DAH

The results revealed literature published between 1998 and 2013, with approximately half of the publications produced in the last five years (n=34, published between January 2008 and February 2013), by authors predominantly working in the United States (n=26), the United Kingdom (n=14) and Australia (n=13) (Table 2).

The majority of papers (n=43) involved 'young people' aged between 10 and 24 years old [19]. Some (n=12) exclusively studied adolescents (between 10 and 19 years old) [2] and the others (n=31) people aged up to 25 years and/or drew on concepts such as 'young people' or 'youth' [2]. Only a small number (n=7) linked DAH exclusively to 'adults' or 'young adults', and fewer (n=4) to children under age 10 years (Table 3).

Regarding the research topic/area, the majority of papers (n=38) addressed the topic of transition from child to adult-centred healthcare (Table 4). The remainder explored different aspects of adolescent development (n=9), specific conditions (n=9), healthcare provision (n=4) and chronic illness (n=2).

Table 5 shows the health condition to which the use of the term DAH was linked. The majority (n=51) were studies of chronic conditions, either focussing on specific chronic conditions (n=34) such as Diabetes, Congenital Heart Disease, Juvenile Idiopathic Arthritis

and Cancer; or on generic categories (n=17) such as chronic illness, special health care needs, cognitive impairment and intellectual disabilities.

The meanings of the term DAH

The term DAH was referred to 85 times within the data set, in addition to the prefix 'developmentally appropriate' being referred to 58 times, with only one manuscript providing an explicit definition: '[DAH is] a set of clinical practices oriented to concomitantly achieving better developmental and health outcomes for young people' [20]. Beyond this, content analysis identified other core ideas attached to the term and a wider range of definition that could be inferred from its use.

DAH is considered a 'key principle underpinning the practice of adolescent medicine' [20]. To deliver DAH, 'the key developmental tasks facing adolescents and young adults need to be taken into consideration' [12]. DAH requires health care professionals to 'have an appreciation for emerging adulthood' [12]; to 'maintain awareness of adolescent development in their interactions with young people and their parents' [20]; and to acknowledge that development occurs at a 'physical, psychosocial and cognitive' level [8,20,21] including the assumption that 'experimentation is part of "normal" adolescent psychosocial development but becomes concerning when it evolves into risk-taking behaviour' [8].

Adolescent development entails another key aspect of the term DAH, which is its 'comprehensiveness' [22–25]. The provision of DAH involves taking into account 'how their health care goals fit with their other life-goals' [11] and 'how their life circumstances and occupational choices influence their approach to self-management' [26], which includes their 'need to receive developmentally appropriate health promotion and anticipatory guidance' [27] as well as disease education and skills training [8,11,28]. This will enable young people 'to integrate their disease management into their overall life projects in order to achieve a high quality of life and be able to undertake active participation in society as a whole' [27].

Another key aspect within the concept of DAH is the idea of 'continuity' [11,22,23,25,29], even 'after the age of 18' [11,12,27]. DAH is required 'whether young people are still based within a paediatric service or whether they have transferred to an adult setting' [28] and therefore involves developing a 'young-person-friendly service, irrespective of setting' [30]. DAH is an ongoing process, 'patient-centred' [8,20,22,23,25] and 'responsive' [8,12,22,23,25,27] to the young person's developmental stage rather than chronological age [21,29,31–33], as an arbitrary age point as a sole criterion 'may disregard the complexity of adolescent development' [29]. DAH implies delivery of care in a sound, uninterrupted manner [21,22,28,30,34] regardless of the healthcare setting or the clinical team.

Finally, provision of DAH involves 'flexibility' [12,21–23,25] in healthcare delivery for young people, either emphasising or creating it [12], in aspects such as to 'make treatment decisions that meet their needs, and negotiate the advantages and disadvantages inherent in such decisions' [26]. Flexibility is key to providing a healthcare service of a pace and intensity that can vary according to developmental needs [21,29,31–33], which in turn may vary according to individual differences or potential delays in the context of chronic illness [8,21].

DISCUSSION

Irrespective of age, DAH formulates healthcare by taking the patient's developmental stage as the starting point for appropriate provision [21,29,31–33]. Professionals working with

young people should therefore advocate such an approach. However, considering the wealth of existing adolescent health literature, it is surprising that the term was found in relatively few papers and only explicitly defined in one of them. There were also important aspects of adolescent development that were absent from the literature, for example the changing role of the parent and professional.

Authors from established adolescent health programmes, whether clinical or research, may simply accept the term as so fundamental to their practice that it does not need to be defined or stated. However, adolescent developmental milestones may not always receive equivalent attention in paediatric training programmes as the classic lists of developmental milestones for younger children receive. In a survey of paediatric professionals, 22, 29 and 33% of staff reported low/very low levels of knowledge, confidence and skill respectively in the area of biopsychosocial development during adolescence [35]. Therefore whilst there are still countries such as the UK where adolescent health/medicine is not a distinct discipline, there is a need for clarity and consensus of what DAH means in order to ensure that DAH is delivered to young people universally in the future [28].

A definition of DAH for young people will need to: (i) acknowledge that development occurs and progresses at a physical, cognitive and psychosocial level in an interdependent manner; (ii) acknowledge the changing roles of parents and professionals during adolescent development; (iii) incorporate strategies to empower young people in terms of autonomy and promote their ability to take on responsibility for their own healthcare; (iv) facilitate the integration of their health management into their overall life projects and contexts.

Furthermore, there are three key aspects that should be considered so as to contextualise such definition:

First, the use of the term DAH is tied to adolescent health related issues or adolescent medicine. Also, the literature mainly focused on the adolescent developmental stage (10-19 years), either exclusively or as incorporated into an age range up until 25 in keeping with the WHO definition of young people [2]. In practice, this aspect is exemplified by the intrinsic nature of routine psychosocial screening, consideration of risk and protective factors and assurance of confidentiality in DAH for young people [35]. In view of the neuroscience advances reporting that brain development continues into the third decade [36], the relevance of DAH in clinical settings where adolescents and young adults are seen - whether in primary care, paediatrics, adult medicine – is only likely to grow in importance and significance.

Second, there is a close relationship between the term DAH and the concept of transition [28]. Many of the papers focused on the topic of transition from child to adult-centred healthcare and the term DAH has been widely used as a defining feature of the concept of transition. However, in the light of the conceptualisation of DAH, transition to adult healthcare should be understood as intrinsic to the overall clinical implementation of DAH for young people [28]. All young people, irrespective of health status, will (hopefully) make the transition from child to adult services. Transition should be considered within the broader arena of adolescent health and no longer distinctly separate [37] nor solely about the event of transfer [38]. Increasingly there is a call for adoption of a life-course approach to adolescent health [3]. Rather than considering only the impact of change of service provider, we should consider how to address all the needs of young people at this stage of their life-course [39], bearing in mind that health transition is just one of many transitions during adolescence (for example social, cultural and economic), and that each transition area may influence the other.

And third, there is a link between the use of the term DAH and chronic conditions. Individuals with chronic conditions are at higher risk than their peers for unnecessary dependency,

psychosocial delay, risk taking behaviours and other developmental difficulties [28,40–42]. Accordingly, the study identified a focus on a range of chronic conditions as well as a body of literature that recognises and advocates the non-categorical approach to chronic conditions (Table 5). However, it was surprising that there were not more papers identified addressing DAH in the context of learning disability (Table 5). In such circumstances, careful consideration of both chronological age as well as developmental stage are imperative in the care of young people [43,44].

Next steps

Beyond acceptance of a definition of DAH for young people, it will also be important to reach a consensus among professionals and researchers about at least three critical aspects of the DAH concept, regarding age ranges and developmental stages:

- a. *The wide heterogeneous diversity in terminology.* Consensus about this would mean greater clarity around research which is focussed on transfer, transition and/or adolescent/young adult health, thereby providing such research with greater impetus and better focus than has been achieved to date.
- b. *The wide diversity of age ranges.* Age range diversity makes it difficult to aggregate and/or compare results across studies. The lack of age range specificity risks the loss of important adolescent-specific data, e.g. the 10-14 year old data of early adolescence when only 15+ year old data is considered [4,38].
- c. *The boundaries of DAH for young people.* Over half the literature discussed adult participants, whether it was as ‘young adults’, ‘young people’, ‘youth’ or ‘adults’. This poses the following question: when does DAH for young people end? Brain development is now known to continue into and beyond the mid-twenties [36,45] and social developmental milestones such as living independently are being shifted further into the third decade. One could argue that developmental appropriateness in healthcare provision is as important for emerging adults (19-25 years) as it is for adolescents (10-19 years) [8,12,27]. This is reflected in the evidence to support calls for development of young adult clinics for young people with long-term conditions, rather than just limiting service development to the “transition clinic” concept [6,7,46].

Therefore, beyond acceptance of a definition, it will also be important in the future to reach a consensus about the critical aspects of the concept. To address this and move the field forward, we are plan to undertake a Delphi study [47–49] involving experts from the field in order to achieve formal consensus on the content and range of the definition of DAH for young people at both conceptual and operational levels.

CONCLUSIONS

This paper has identified a link between the use of the term ‘developmentally appropriate healthcare’ and the domains of adolescent medicine, young people with chronic conditions and the concept of transition. There is a need for consistency in the use of the term DAH for young people as well as in the related stage-of-life terminology and age range cut-off points.

The next steps will be to establish consensus about the content and range of a formal conceptual and operational definition. This will facilitate the production of a stronger body of evidence for developmentally appropriate healthcare services for young people and contribute to the further development of the practical implications and quality criteria for such services. In so doing, DAH for young people could potentially become a model quality measure for all healthcare across the lifespan, as all people of any age require DAH provided by staff with the appropriate expertise.

ACKNOWLEDGEMENTS

The authors would like to thank their fellow co-applicants of the TRANSITION Research Programme for their help and advice: Angela Bate, Allan Colver, Ann Le Couteur, Gail Dovey-Pearce, Helen McConachie, Mark Pearce, Luke Vale, Helen Wheatley.

FOOTNOTES

Contributors

Study design JMcd and AF; scoping review and content analysis AF; second reviewer VW; supervision of study JMcd; write-up of drafts JMcd and AF; critical review of the manuscript All Authors.

Competing interests

None

Funding

This study arose as part of the Transition Research Programme, which is independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0610-10112). The views expressed in this article are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

REFERENCES

- 1 Viner R. Chapter 8, Life stage: Adolescence. In: *Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays*. London: 2013.
- 2 World Health Organization. *The second decade: improving adolescent health and development*. Geneva: 2001.
- 3 Sawyer SM, Afifi RA, Bearinger LH, *et al*. Adolescence: a foundation for future health. *The Lancet* 2012;**379**:1630–40. doi:10.1016/S0140-6736(12)60072-5
- 4 Payne D. Meeting the needs of young people in hospital. *Arch Dis Child* 2013;**98**:930–2. doi:10.1136/archdischild-2013-304294
- 5 Ambresin A-E, Bennett K, Patton GC, *et al*. Assessment of Youth-Friendly Health Care: A Systematic Review of Indicators Drawn From Young People's Perspectives. *J Adolesc Health* 2013;**52**:670–81. doi:10.1016/j.jadohealth.2012.12.014
- 6 Harden PN, Walsh G, Bandler N, *et al*. Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure. *BMJ* 2012;**344**:e3718–e3718. doi:10.1136/bmj.e3718
- 7 Crowley R, Wolfe I, Lock K, *et al*. Improving the transition between paediatric and adult healthcare: a systematic review. *Arch Dis Child* 2011;**96**:548–53. doi:10.1136/ad.2010.202473

- 8 McDonagh JE. Growing up and moving on: Transition from pediatric to adult care. *Pediatr Transplant* 2005;**9**:364–72. doi:10.1111/j.1399-3046.2004.00287.x
- 9 Shaw KL, Watanabe A, Rankin E, *et al.* Walking the talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility. *Child Care Health Dev* 2013;;n/a–n/a. doi:10.1111/cch.12110
- 10 Snow R, Fulop N. Understanding issues associated with attending a young adult diabetes clinic: a case study. *Diabet Med* 2012;**29**:257–9. doi:10.1111/j.1464-5491.2011.03447.x
- 11 Dovey-Pearce G, Hurrell R, May C, *et al.* Young adults' (16–25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. *Health Soc Care Community* 2005;**13**:409–19. doi:10.1111/j.1365-2524.2005.00577.x
- 12 D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer* 2011;**117**:2329–34. doi:10.1002/cncr.26043
- 13 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;**8**:19–32. doi:10.1080/1364557032000119616
- 14 Armstrong R, Hall BJ, Doyle J, *et al.* 'Scoping the scope' of a cochrane review. *J Public Health* 2011;**33**:147–50. doi:10.1093/pubmed/fdr015
- 15 Hsieh H-F, Shannon SE. Three Approaches to Qualitative Content Analysis. *Qual Health Res* 2005;**15**:1277–88. doi:10.1177/1049732305276687
- 16 Potter WJ, Levine-Donnerstein D. Rethinking validity and reliability in content analysis. *J Appl Commun Res* 1999;**27**:258–84. doi:10.1080/00909889909365539
- 17 Kondracki NL, Wellman NS, Amundson DR. Content Analysis: Review of Methods and Their Applications in Nutrition Education. *J Nutr Educ Behav* 2002;**34**:224–30. doi:10.1016/S1499-4046(06)60097-3
- 18 Graneheim U., Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;**24**:105–12. doi:10.1016/j.nedt.2003.10.001
- 19 World Health Organization. Young people's health — a challenge for society: report of a WHO Study Group on Young People and 'Health for All by the Year 2000'. Geneva: WHO 1986.
- 20 Sawyer SM, Aroni RA. Self-management in adolescents with chronic illness. What does it mean and how can it be achieved? *Med J Aust* 2005;**183**:405–9.
- 21 McDonagh JE. Transition of care from paediatric to adult rheumatology. *Arch Dis Child* 2007;**92**:802–7. doi:10.1136/adc.2006.103796
- 22 American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs. *Pediatrics* 2002;**110**:1304–6.

- 23 Wang G, McGrath BB, Watts C. Health Care Transitions Among Youth With Disabilities or Special Health Care Needs: An Ecological Approach. *J Pediatr Nurs* 2010;**25**:505–50. doi:10.1016/j.pedn.2009.07.003
- 24 Baglia J, Foster E, Dostal J, *et al.* Generating developmentally appropriate competency assessment at a family medicine residency. *Fam Med* 2011;**43**:90–8.
- 25 Forman S, Woods E. Youth, risks, and chronic illness. *Curr Opin Pediatr August 2011* 2011;**23**:365–6. doi:10.1097/MOP.0b013e3283481118
- 26 Pyatak E. Participation in Occupation and Diabetes Self-Management in Emerging Adulthood. *J Occup Ther July 2011*; **65**:462–9. doi:10.5014/ajot.2011.001453
- 27 Berg Kelly K. Sustainable transition process for young people with chronic conditions: a narrative summary on achieved cooperation between paediatric and adult medical teams. *Child Care Health Dev* 2011;**37**:800–5. doi:10.1111/j.1365-2214.2011.01330.x
- 28 Sawyer SM. Developmentally appropriate healthcare for young people with chronic illness: Questions of philosophy, policy, and practice. *Pediatr Pulmonol* 2003;**36**:363–5. doi:10.1002/ppul.10369
- 29 While A, Forbes A, Ullman R, *et al.* Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child Care Health Dev* 2004;**30**:439–52. doi:10.1111/j.1365-2214.2004.00440.x
- 30 McDonagh J. Getting it right for young people: developing adolescent rheumatology services. *Future Rheumatol April 2008* 2008;**3**:133–41. doi:10.2217/17460816.3.2.133
- 31 Herzer M, Goebel J, Cortina S. Transitioning cognitively impaired young patients with special health needs to adult-oriented care: collaboration between medical providers and pediatric psychologists. *Curr Opin Pediatr Oct 2010* 2010;**22**:668–72. doi:10.1097/MOP.0b013e32833c3609
- 32 Fredericks EM, Dore-Stites D, Lopez MJ, *et al.* Transition of pediatric liver transplant recipients to adult care: Patient and parent perspectives. *Pediatr Transplant* 2011;**15**:414–24. doi:10.1111/j.1399-3046.2011.01499.x
- 33 Breakey VR, Blanchette VS, Bolton-Maggs PHB. Towards comprehensive care in transition for young people with haemophilia. *Haemophilia* 2010;**16**:848–57. doi:10.1111/j.1365-2516.2010.02249.x
- 34 Schrandt-Stumpel CTRM, Sinnema M, van den Hout L, *et al.* Healthcare transition in persons with intellectual disabilities: General issues, the Maastricht model, and Prader–Willi syndrome. *Am J Med Genet C Semin Med Genet* 2007;**145C**:241–7. doi:10.1002/ajmg.c.30136
- 35 McDonagh JE, Minnaar G, Kelly K, *et al.* Unmet education and training needs in adolescent health of health professionals in a UK children’s hospital. *Acta Paediatr* 2006;**95**:715–9.

- 36 Colver A, Longwell S. New understanding of adolescent brain development: relevance to transitional healthcare for young people with long term conditions. *Arch Dis Child* 2013;**98**:902–7. doi:10.1136/archdischild-2013-303945
- 37 Kennedy A, Sawyer S. Transition from pediatric to adult services: are we getting it right? *Curr Opin Pediatr August 2008* 2008;**20**:403–9. doi:10.1097/MOP.0b013e328305e128
- 38 McDonagh JE, Kelly DA. The challenges and opportunities for transitional care research. *Pediatr Transplant Sept 2010* 2010;**14**:688–700. doi:10.1111/j.1399-3046.2010.01343.x
- 39 Allen D, Gregory J. The transition from children’s to adult diabetes services: understanding the ‘problem’. *Diabet Med* 2009;**26**:162–6. doi:10.1111/j.1464-5491.2008.02647.x
- 40 Rosen DS. Transition of young people with respiratory diseases to adult health care. *Paediatr Respir Rev* 2004;**5**:124–31. doi:10.1016/j.prrv.2004.01.008
- 41 Surís J-C, Michaud P-A, Akre C, *et al.* Health Risk Behaviors in Adolescents With Chronic Conditions. *Pediatrics* 2008;**122**:e1113–e1118. doi:10.1542/peds.2008-1479
- 42 Sawyer SM, Drew S, Yeo MS, *et al.* Adolescents with a chronic condition: challenges living, challenges treating. *The Lancet* 2007;**369**:1481–9. doi:10.1016/S0140-6736(07)60370-5
- 43 Kaufman M. Transition of cognitively delayed adolescent organ transplant recipients to adult care. *Pediatr Transplant* 2006;**10**:413–7. doi:10.1111/j.1399-3046.2006.00491.x
- 44 Gleeson H, Turner G. Transition to adult services. *Arch Dis Child - Educ Pract Ed* 2012;**97**:86–92. doi:10.1136/archdischild-2011-300261
- 45 Steinberg L. A behavioral scientist looks at the science of adolescent brain development. *Brain Cogn* 2010;**72**:160–4. doi:10.1016/j.bandc.2009.11.003
- 46 Jordan A, McDonagh JE. Recognition of emerging adulthood in UK rheumatology: the case for young adult rheumatology service developments. *Rheumatology* 2007;**46**:188–91. doi:10.1093/rheumatology/kel368
- 47 Murphy E, Black N, Lamping D, *et al.* Consensus development methods, and their use in clinical guideline development: a review. *Health Technol Assess* 1998;**2**:88. doi:10.3310/hta2030
- 48 Jones J, Hunter D. Qualitative Research: Consensus methods for medical and health services research. *BMJ* 1995;**311**:376–80. doi:10.1136/bmj.311.7001.376
- 49 Vella K, Goldfrad C, Rowan K, *et al.* Use of consensus development to establish national research priorities in critical care. *BMJ* 2000;**320**:976–80. doi:10.1136/bmj.320.7240.976

TABLES

Table 1 - Articles included in the study.

ID	Full Reference	Type of Article
1	Aberg JA, Kaplan JE, Libman H, Emmanuel P, Anderson JR, Stone VE, et al. Primary Care Guidelines for the Management of Persons Infected with Human Immunodeficiency Virus: 2009 Update by the HIV Medicine Association of the Infectious Diseases Society of America. <i>Clin Infect Dis</i> . 2009 Sep 1;49(5):651–81.	Review Article
2	Allen D, Gregory J. The transition from children’s to adult diabetes services: understanding the “problem”. <i>Diabetic Medicine</i> . 2009;26(2):162–6.	Primary Research
3	American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs. <i>Pediatrics</i> . 2002 Dec 1;110(Supplement 3):1304–6.	Theoretical/Opinion
4	Anderson BJ, McKay SV. Barriers to glycemic control in youth with type 1 diabetes and type 2 diabetes. <i>Pediatric Diabetes</i> . 2011;12(3pt1):197–205.	Review Article
5	Atun-Einy O, Scher A. Measuring developmentally appropriate practice in neonatal intensive care units. <i>Journal of Perinatology</i> . 2008 Mar;28(3):218–25.	Primary Research
6	Baglia J, Foster E, Dostal J, Keister D, Biery N, Larson D. Generating developmentally appropriate competency assessment at a family medicine residency. <i>Fam Med</i> . 2011 Feb;43(2):90–8.	Primary Research
7	Berg Kelly K. Sustainable transition process for young people with chronic conditions: a narrative summary on achieved cooperation between paediatric and adult medical teams. <i>Child: Care, Health and Development</i> . 2011;37(6):800–5.	Primary Research
8	Breakey VR, Blanchette VS, Bolton-Maggs PHB. Towards comprehensive care in transition for young people with haemophilia. <i>Haemophilia</i> . 2010;16(6):848–57.	Review Article
9	Callahan ST, Winitzer RFM, Keenan PR. Transition from pediatric to adult-oriented health care: a challenge for patients with chronic disease. <i>Current Opinion in Pediatrics</i> August 2001. 2001;13(4):310–6.	Theoretical/Opinion
10	Coleman R, Moore S. Future considerations in the transition of paediatric neuro-developmental patients to adult services. <i>Australasian Journal of Neuroscience</i> . 2006;15.	Theoretical/Opinion
11	Cooley WC, Sagerman PJ. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. <i>Pediatrics</i> . 2011 Jul 1;128(1):182–200.	Theoretical/Opinion
12	D’Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. <i>Cancer</i> . 2011;117(S10):2329–34.	Theoretical/Opinion
13	Dovey-Pearce G, Doherty Y, May C. The influence of diabetes upon adolescent and young adult development: A qualitative study. <i>British Journal of Health Psychology</i> . 2007;12(1):75–91.	Primary Research
14	Dovey-Pearce G, Hurrell R, May C, Walker C, Doherty Y. Young adults’ (16–25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. <i>Health & Social Care in the Community</i> . 2005;13(5):409–19.	Primary Research
15	Drew S. “Having cancer changed my life, and changed my life forever”: survival, illness legacy and service provision following cancer in childhood. <i>Chronic Illness</i> . 2007 Dec 1;3(4):278–95.	Primary Research
16	Duncan RE, Gillam L, Savulescu J, Williamson R, Rogers JG, Delatycki MB. The challenge of developmentally appropriate care: predictive genetic testing in young people for familial adenomatous polyposis. <i>Familial Cancer</i> . 2009 Sep 17;9(1):27–35.	Primary Research
17	Edidin JP, Ganim Z, Hunter SJ, Karnik NS. The Mental and Physical Health of Homeless Youth: A Literature Review. <i>Child Psychiatry & Human Development</i> . 2011 Nov 26;43(3):354–75.	Review Article
18	Ewing JE. Are we doing enough for young people with chronic illness? <i>Australian and New Zealand Journal of Public Health</i> . 2003;27(5):560–560.	Editorial/Commentary

19	Forman SF, Woods ER. Youth, risks, and chronic illness. <i>Current Opinion in Pediatrics</i> . 2011 Aug;23(4):365–6.	Editorial/Commentary
20	Fredericks EM, Dore-Stites D, Lopez MJ, Well A, Shieck V, Freed GL, et al. Transition of pediatric liver transplant recipients to adult care: Patient and parent perspectives. <i>Pediatric Transplantation</i> . 2011;15(4):414–24.	Primary Research
21	Herzer M, Goebel J, Cortina S. Transitioning cognitively impaired young patients with special health needs to adult-oriented care: collaboration between medical providers and pediatric psychologists. <i>Current Opinion in Pediatrics</i> October 2010. 2010;22(5):668–72.	Editorial/Commentary
22	Hilderson D, Moons P, Westhovens R, Wouters C. Attitudes of rheumatology practitioners toward transition and transfer from pediatric to adult healthcare. <i>Rheumatology International</i> . 2011 Dec 23;32(12):3887–96.	Primary Research
23	Hink H, Schellhase D. Transitioning Families to Adult Cystic Fibrosis Care. <i>Journal for Specialists in Pediatric Nursing</i> October 2006. 2006;11(4):260–3.	Theoretical/Opinion
24	Holzheimer, Mohay, Masters. Educating young children about asthma: comparing the effectiveness of a developmentally appropriate asthma education video tape and picture book. <i>Child: Care, Health and Development</i> . 1998;24(1):85–99.	Primary Research
25	Kennedy A, Sloman F, Douglass J, Sawyer S. Reply. <i>Internal Medicine Journal</i> . 2008;38(5):378–9.	Editorial/Commentary
26	Kennedy A, Sawyer S. Transition from pediatric to adult services: are we getting it right? <i>Current Opinion in Pediatrics</i> . Aug 2008;20(4):403–9.	Review Article
27	Levine L, Levine M. Health care transition in thalassemia: pediatric to adult-oriented care. <i>Annals of the New York Academy of Sciences</i> . 2010;1202(1):244–7.	Theoretical/Opinion
28	Losavio K. 11 Steps to a Successful Transition. <i>The Hospitalist</i> . March 2006.	Editorial/Commentary
29	Macfarlane A, Blum RW. Do we need specialist adolescent units in hospitals? <i>BMJ</i> . Apr 2001;322(7292):941–2.	Editorial/Commentary
30	McCurdy C, DiCenso A, Boblin S, Ludwin D, al et. There to here: young adult patients' perceptions of the process of transition from pediatric to adult transplant care. <i>Progress in Transplantation</i> . 2006 Dec;16(4):309–16.	Primary Research
31	McDonagh JE, Kelly DA. The challenges and opportunities for transitional care research. <i>Pediatric Transplantation</i> September 2010. 2010;14(6):688–700.	Theoretical/Opinion
32	McDonagh JE, Southwood TR, Shaw KL. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. <i>Rheumatology</i> . 2007 Jan 1;46(1):161–8.	Primary Research
33	McDonagh J. Getting it right for young people: developing adolescent rheumatology services. <i>Future Rheumatology</i> April 2008. 2008;3(2):133–41.	Theoretical/Opinion
34	McDonagh JE. Transition of care from paediatric to adult rheumatology. <i>Arch Dis Child</i> . 2007 Sep;92(9):802–7.	Review Article
35	McDonagh JE. Has the gap been bridged yet? Young people in paediatric and adult rheumatology. <i>Rheumatology (Oxford)</i> . 2013 Jan 25;[Epub ahead of print].	Editorial/Commentary
36	McDonagh JE, Kelly DA. Transitioning care of the pediatric recipient to adult caregivers. <i>Pediatric Clinics of North America</i> . 2003 Dec;50(6):1561–83.	Theoretical/Opinion
37	McDonagh JE. Growing up and moving on: Transition from pediatric to adult care. <i>Pediatric Transplantation</i> . 2005;9(3):364–72.	Theoretical/Opinion
38	Moons P, Hilderson D, Deyk KV. Implementation of Transition Programs can Prevent Another Lost Generation of Patients with Congenital Heart Disease. <i>Eur J Cardiovasc Nurs</i> . 2008 Dec 1;7(4):259–63.	Theoretical/Opinion
39	Moons P, Pinxten S, Dedroog D, Van Deyk K, Gewillig M, Hilderson D, et al. Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. <i>Journal of adolescent health</i> . 2009;44(4):316–22.	Primary Research
40	Newman L, Birlleson P. Mental health planning for children and youth: is it developmentally appropriate? <i>Australas Psychiatry</i> . 2012 Apr 1;20(2):91–7.	Theoretical/Opinion
41	Pahl E, Grady KL. Pediatric Heart Transplantation: Transitioning to Adult Care. <i>ISHLTLinks</i> . April 2012;11(3).	Theoretical/Opinion
42	Pyatak E. Participation in Occupation and Diabetes Self-Management in Emerging Adulthood. <i>Journal of Occupational Therapy</i> July. 2011;65(4):462–9.	Primary Research
43	Reiss J. Long-term outcomes for extremely low-birth-weight infants. <i>JAMA</i> . 2005 Nov 2;294(17):2168–9.	Editorial/Commentary
44	Robinson WL, Harper GW, Schoeny ME. Reducing Substance Use Among African American Adolescents: Effectiveness of School-Based Health Centers. <i>Clinical Psychology: Science and Practice</i> . 2003;10(4):491–504.	Primary Research

45	Rosen DS. Transition of young people with respiratory diseases to adult health care. <i>Paediatric Respiratory Reviews</i> . 2004;5(2):124–31.	Theoretical/Opinion
46	Sable C, Foster E, Uzark K, Bjornsen K, Canobbio MM, Connolly HM, et al. Best Practices in Managing Transition to Adulthood for Adolescents With Congenital Heart Disease: The Transition Process and Medical and Psychosocial Issues A Scientific Statement From the American Heart Association. <i>Circulation</i> . 2011 Apr 5;123(13):1454–85.	Theoretical/Opinion
47	Saidi A, Kovacs AH. Developing a Transition Program from Pediatric- to Adult-Focused Cardiology Care: Practical Considerations. <i>Congenital Heart Disease</i> . 2009;4(4):204–15.	Theoretical/Opinion
48	Sawyer SM. In search of quality care for adolescents and young adults with chronic conditions. <i>Journal of Paediatrics and Child Health</i> . 2008;44(9):475–7.	Editorial/Commentary
49	Sawyer SM. Developmentally appropriate healthcare for young people with chronic illness: Questions of philosophy, policy, and practice. <i>Pediatric Pulmonology</i> . 2003;36(5):363–5.	Theoretical/Opinion
50	Sawyer SM, Aroni RA. Self-management in adolescents with chronic illness. What does it mean and how can it be achieved? <i>Medical Journal of Australia</i> . 2005 Oct 17;183(8):405–9.	Theoretical/Opinion
51	Sawyer SM, Macnee S. Transition to adult health care for adolescents with spina bifida: Research issues. <i>Developmental Disabilities Research Reviews</i> . 2010;16(1):60–5.	Theoretical/Opinion
52	Schrander-Stumpel CTRM, Sinnema M, Van den Hout L, Maaskant MA, Van Schrojenstein Lantman-de Valk HMJ, Wagemans A, et al. Healthcare transition in persons with intellectual disabilities: General issues, the Maastricht model, and Prader–Willi syndrome. <i>American Journal of Medical Genetics Part C: Seminars in Medical Genetics</i> . 2007;145C(3):241–7.	Theoretical/Opinion
53	Shaw KL, Southwood TR, McDonagh JE. Transitional care for adolescents with juvenile idiopathic arthritis: a Delphi study. <i>Rheumatology</i> . 2004 Aug 1;43(8):1000–6.	Primary Research
54	Srivastava SA, Elkin SL, Bilton D. The Transition of Adolescents with Chronic Respiratory Illness to Adult Care. <i>Paediatric Respiratory Reviews</i> . Dec 2012;13(4):230-235.	Theoretical/Opinion
55	Telfair J, Alleman-Velez PL, Dickens P, Loosier PS. Quality Health Care for Adolescents with Special Health-Care Needs: Issues and Clinical Implications. <i>Journal of Pediatric Nursing</i> . 2005 Feb;20(1):15–24.	Theoretical/Opinion
56	Towns SJ, Sawyer SM, Stephens L, Clarke SD, Bennett DL. Hospital based care of young people in Australia. <i>International Journal of Adolescent Medicine and Health</i> . 2007;19(3):317–23.	Theoretical/Opinion
57	Tuffrey C, Pearce A. Transition from paediatric to adult medical services for young people with chronic neurological problems. <i>J Neurol Neurosurg Psychiatry</i> . 2003 Aug 1;74(8):1011–3.	Editorial/Commentary
58	Wang G, McGrath BB, Watts C. Health Care Transitions Among Youth With Disabilities or Special Health Care Needs: An Ecological Approach. <i>Journal of Pediatric Nursing</i> . 2010 Dec;25(6):505–50.	Review Article
59	Weissberg-Benchell J, Wolpert H, Anderson BJ. Transitioning From Pediatric to Adult Care A new approach to the post-adolescent young person with type 1 diabetes. <i>Dia Care</i> . 2007 Oct 1;30(10):2441–6.	Editorial/Commentary
60	While A, Forbes A, Ullman R, Lewis S, Mathes L, Griffiths P. Good practices that address continuity during transition from child to adult care: synthesis of the evidence. <i>Child: Care, Health and Development</i> . 2004;30(5):439–52.	Review Article
61	White PH. On the road to adulthood for youth with rheumatic diseases: What health care professionals can do. <i>Arthritis Care & Research</i> . 2008;59(8):1054–7.	Editorial/Commentary
62	Underinsurance impacts teens’ access to care. <i>Contraceptive Technology Update</i> . Jul 2009;30(7):76.	Theoretical/Opinion

Table 2 - Distribution of the literature by year of publication and country of institutional affiliation of the authors.

	Country of institutional affiliation								Total
	Australia	Belgium	Canada	Israel	Netherlands	Sweden	UK	USA	
1998	1								1
2001								2	2
2002								1	1
2003	2						2	1	5
2004							2	1	3
2005	1						2	2	5
2006	1		1					2	4
2007	2				1		3	1	7
2008	3	1		1			1	1	7
2009	1	1					1	3	6
2010	1		1				1	3	6
2011		1	1			1		8	11
2012	1						1	1	3
2013							1		1
Total	13	3	3	1	1	1	14	26	62

Table 3 - Distribution of the literature by age group and/or developmental stage to which the use of the concept was linked.

Age and Stage	Number of sources (n = 62)
Age and stage defined	18 (29.03%)
02-05 (young children)	1 (1.61%)
10-19 (adolescents)	2 (3.23%)
10-24 (young people)	2 (3.23%)
10-25 (young people)	1 (1.61%)
10-25 (youth)	1 (1.61%)
11,14 & 17 (adolescents)	1 (1.61%)
12-19 (adolescents)	1 (1.61%)
12-21 (adolescent and young adult)	1 (1.61%)
12-25 (young people)	1 (1.61%)
15-17 (adolescents)	1 (1.61%)
15-29 (adolescent and young adult)	1 (1.61%)
16-25 (young adults)	1 (1.61%)
18-30 (post-adolescent young persons)	1 (1.61%)
19-25 (young adults)	1 (1.61%)
Adolescents (11-15) and young adults (16-25)	1 (1.61%)
Adolescents (11-18) and youth	1 (1.61%)
Age but not stage defined	1 (1.61%)
18-28	1 (1.61%)
Stage but not age defined	35 (56.45%)
Adolescents	7 (11.29%)
Adolescents and young adults	2 (3.23%)
Adults	1 (1.61%)
Children	2 (3.23%)
Neonatal	1 (1.61%)
Young adults	2 (3.23%)
Young people	15 (24.19%)
Youth	5 (8.06%)
Neither age nor stage defined	8 (12.90%)
Young patients	2 (3.23%)
Not Applicable	6 (9.68%)

Table 4 - Distribution of the literature by topic/area of research.

Topic linked	Number of sources (n = 62)
Transitional care	38 (61.29%)
Transition	38 (61.29%)
Healthcare provision	4 (6.45%)
Access to care	1 (1.61%)
Primary care	1 (1.61%)
Hospital based care of young people	1 (1.61%)
Specialist adolescent units	1 (1.61%)
Topics related to adolescent development	9 (14.51%)
Quality care for adolescents and young adults	2 (3.23%)
Adolescent and young adult development	1 (1.61%)
Developmentally Appropriate Competency	1 (1.61%)
Self-management	2 (3.23%)
Developmentally appropriate healthcare	1 (1.61%)
Developmentally Appropriate Practice	1 (1.61%)
Developmentally Appropriate Psychosocial Care	1 (1.61%)
Topics related to specific areas, conditions or specialties	9 (14.51%)
Long-term outcomes for extremely low-birth-weight infants	1 (1.61%)
Predictive genetic testing	1 (1.61%)
Mental health of homeless youth	1 (1.61%)
Mental health planning	1 (1.61%)
Substance use	1 (1.61%)
Glycemic control	1 (1.61%)
Developmentally appropriate diabetes services	1 (1.61%)
Developmentally appropriate asthma education	1 (1.61%)
Survival, illness legacy and service provision following cancer in childhood	1 (1.61%)
Topics related to chronic illness as a generic category	2 (3.23%)
Young people with chronic illness	1 (1.61%)
Youth, risks and chronic illness	1 (1.61%)

Table 5 - Distribution of the literature by condition to which the use of the concept was linked.

Condition or Specialty linked	Number of sources (n = 62)
<u>Generic Categories</u>	20 (32.24%)
Chronic illness	12 (19.35%)
Special Health Care Needs	3 (4.84%)
Cognitive impairment	1 (1.61%)
Intellectual disabilities	1 (1.61%)
Family medicine residency	1 (1.61%)
Psychiatry	1 (1.61%)
Reproductive health	1 (1.61%)
<u>Condition-Specific</u>	35 (56.42%)
Diabetes	6 (9.68%)
Rheumatology (total)	6 (9.68%)
- Rheumatology	4 (6.45%)
- Juvenile idiopathic arthritis	2 (3.23%)
Transplantation (total)	6 (9.68%)
- Transplant care	5 (8.06%)
- Liver transplant recipients	1 (1.61%)
Cardiology (total)	4 (6.45%)
- Cardiology care	1 (1.61%)
- Congenital Heart Disease	3 (4.84%)
Cancer (total)	3 (4.84%)
- Cancer	1 (1.61%)
- Cancer survivors	2 (3.23%)
Respiratory (total)	3 (4.83%)
- Respiratory diseases	1 (1.61%)
- Asthma	1 (1.61%)
- Cystic Fibrosis	1 (1.61%)
Hematology (total)	2 (3.22%)
- Hemophilia	1 (1.61%)
- Thalassemia	1 (1.61%)
Neonatal Medicine (total)	2 (3.22%)
- Neonatal intensive care	1 (1.61%)
- Extremely low-birth-weight infants	1 (1.61%)
HIV	1 (1.61%)
Spina bifida	1 (1.61%)
Paediatric neuro-developmental patients	1 (1.61%)
Not applicable	7 (11.29%)